Psychological consequences of admission to the ICU: helping patients and families

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For most patients and their families, admission to the intensive care unit (ICU) is an unanticipated event that causes substantial psychological distress. For patients, short- and long-term consequences include delirium, anxiety, depression, and acute and post-traumatic stress disorders (PTSD).[1] Psychological consequences may be exacerbated by delusions experienced during delirium,[2] which is common and has adverse effects on physical and cognitive function and leads to increased healthcare utilization and costs.[3] For families, anxiety and acute stress arise from concern and uncertainty regarding the prognosis of their family member. Long term psychological effects appear similar to those experienced by patients.[4] Mitigating these effects is increasingly recognised as a core objective of critical care, along with treating and preventing organ failure, prognostic communication, and compassionate end-of-life care when appropriate.

In preceding decades, clinicians conceptualized the ICU as psychologically disturbing and stressful. Limiting exposure of family members (via restricted visiting hours) and patients (via heavy sedation) to this environment was thought to be beneficial for both, and clinicians likely perceived benefits to uninterrupted workflow. This concept led to actions, now viewed as paternalistic, of locked doors and limitations on visiting time and on the number and type of bedside visitors (for example, two at any time and only immediate family), and their removal from the bedside during medical procedures, nursing care, and rounds.

Alternative approaches that may improve psychological outcomes for patients and families are unrestricted family visits to the patient's bedside and recording details of the patient's ICU admission using plain language and images in a diary format. Visiting family members may provide patients with psychological and cognitive support, such as re-orientating and

distracting activities, and participate in care activities to relieve pain and mobilize. In doing so, visitors may also benefit from decreased separation anxiety, less uncertainty and distress relating to prognosis and the treatment plan, and may engage more with the ICU team, facilitating a trusting relationship. Similarly, ICU diaries allow families to document the patient's experience of the ICU admission and serve as a real-time record of events that can be reviewed during admission and after discharge. These functions may decrease anxiety and post-traumatic stress symptoms in both patients and families associated with poor or absent recall of the ICU admission.[5]

In this issue of JAMA, 2 reports focus on psychological well-being of patients and families in the ICU. Rosa and colleagues[6] report findings from a cluster cross-over randomized clinical trial in 36 Brazilian ICUs that examined the effect of a flexible family visiting model (up to 12 hours/day) compared to a restrictive visiting model (median 1.5 hours/day) that was usual practice on the on incidence of delirium. During the intervention phase, family members also attended a structured meeting providing education on the ICU environment, common procedures, the multidisciplinary team, and delirium, received an information brochure, and were given access to a website. The flexible visiting model increased the median duration of family visiting to 4.8 hours vs. 1.4 hours per day in the restricted visiting group ($p<0.001$) but did not influence the number of visitors per day. Despite this increase in visitor time, there were no differences in the primary outcome of incident delirium (18.9% [flexible] versus 20.1% [restricted]; $p=0.44$) or any of the patient-related secondary outcomes.

However, the flexible visiting model reduced the level of psychological distress of family members, measured by the Hospital Anxiety and Depression Scale (HADS), and increased family

satisfaction. Because the intervention included several components, as is often the case in biobehavioral interventions, it cannot be determined if the positive effects for family caregivers were due to flexible visiting hours or improved adaptation to the ICU environment, and whether the mechanism involved greater engagement in shared decision-making. Reassuringly, the benefit for family caregivers did not come at the expense of increased clinician burnout, as assessed by the Maslach Burnout Inventory.

Despite the high ICU-level adherence to flexible visiting hours, the intervention may have been insufficiently intense to influence patient-level outcomes. First, family members enrolled in the study spent less than half of the maximum possible visiting time at the bedside, likely because of competing commitments. Second, even though the intervention cohort received additional education about the ICU environment, no specific instruction about strategies to reduce delirium was reported. Although family members' self-reported involvement in patient care as a tertiary outcome, the trial did not document bedside activities by family members, and analyses did not consider associations between family involvement in care and patient-level outcomes. Arguably, the quality and not the quantity of family visits may influence patient outcomes, and the intervention may have only allowed the presence of the family without enabling them to direct and participate in the delivery of care in a family-centered approach.[7] In addition, there was a suggestion that the flexible model may reduce delirium more in patients with greater illness severity (p-value for interaction of intervention with severity of illness, 0.09), but additional study is needed.

Also in this issue of JAMA, Garrouste-Orgeas and colleagues[8] report the results of a multi-centre (35 French ICUs) randomized clinical trial of an ICU diary completed by both clinicians and

family members. In the intervention group, the diary was provided to the patient, or the family member if the patient was confused, on or close to the day of ICU discharge. If the patient died, the diary and a condolence letter were mailed to the family. Unlike in other trials,[9,10] routine use of a dairy was uncommon in participating centers, and distribution of the diary was not linked to a post-discharge follow-up visit to provide context and support. The control group received usual care without a diary.

The trial recruited 657 patients and their families and found no difference in the primary outcome of post-traumatic stress disorder in ICU survivors (29.9% of ICU diary group participants vs. 34.3% in control participants, p=0.39), measured 90 days after ICU discharge by a blinded psychologist and defined by a score on the Impact of Events Scale-Revised (IES-R) scale >22. There were also no differences in secondary outcomes of PTSD in family members, psychological distress (HADS scores) of either patient or family participants, or patient recall of memories (factual or delusional) of ICU. Moreover, and for unclear reasons, the risk of mortality in the ICU among patients assigned to the diary group was numerically higher than in the control group, although the difference was attenuated at hospital discharge (p-values not reported).

As found with other studies examining the effect of ICU diaries on PTSD,[11] and anticipated in the study design, loss to follow up at 90 days among patient participants was almost 50%; in family participants, loss to follow up was only 14.6%. Notably, 46.4% of family members had PTSD compared to 32.2% of patients. These risks of PTSD may be underestimated, as participants with PTSD may be more avoidant of follow-up that reminds them of the ICU. A high prevalence of PTSD in ICU family members in France has been reported[12] and attributed to a

more paternalistic medical decision-making style that can create discordance with the preferences of family members.[13] Regardless of the mechanism, the findings of this trial underscore the need for effective psychological supports for ICU surviving patients and their family members.

For ICUs that provide patient diaries, this study finds no evidence of harm and therefore provides no reason to stop using them, particularly if their implementation includes other plausibly effective cointerventions, such as mental health support during a structured follow-up visit. However, ICUs that do not provide diaries will find no compelling reason to adopt them. Since Garrouste-Orgeas and colleagues tested the intervention in predominantly diary-naïve ICUs, it is possible that the content and instructions to participants were not sufficiently detailed, at least in the beginning of the trial. An analysis that considers the order of patient enrollment in each centre to reflect experience in delivering the intervention would be informative, as done for other complex interventions.[14]

Perhaps it should come as no surprise that improving psychological outcomes of critically ill patients and their families is as challenging as improving survival in patients with acute respiratory distress syndrome, sepsis, or cardiac arrest. The interventions depend on context; for example, the flexible visitation intervention tested by Rosa et al in Brazil[6] was standard in most ICUs in the study conducted by Garrouste-Orgeas et al in France,[8] and the effect of diaries that require written language commonly understood by the patients, family, and healthcare team may depend on cultural and geographic factors. Future research may require a 'precision' framework to risk-stratify patients and family members for post-discharge anxiety, depression, or PTSD and a tailored ladder of interventions to prevent these outcomes. These may range

from lower intensity approaches of flexible visiting hours with family participation in patient care, with a patient diary and telephone follow-up, to more intensive approaches that include frequent meetings with ICU clinicians and post-ICU follow-up with mental health professionals. Although it would be easy to be dismissive of these two trials to improve post ICU outcomes in patients and families,[6,8] both statistically negative for the primary outcome, their results highlight the high risk of poor psychological outcomes and the heterogeneity of the patients and families at risk.

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